

PATA Newsletter Volume IV Issue 2

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1. Expert Patient Programme to be extended

The One to One Children's Fund announced that they will extend the funding for the PATA expert patient programme from the 33 clinics already participating, to 50 clinics in 2009. Any new clinics that would like to apply to participate can download the application forms from the PATA website or contact info@teampata.org. Applications are due before the 30 April 2009.

2. How clinics will challenge themselves this year

PATA has analyzed the task grids of 32 clinic teams from the Kigali Forum in December 2008 to bring you a summary of clinic tasks for the year ahead. We hope that you'll be inspired to see what everyone will be working towards – both to complete your own tasks and, hopefully, to foster future collaborative efforts between clinics.

Care of the Very Young Infant

Tackling the first Forum theme of Care of the Very Young Infant, 10 clinics aim to strengthen links with **PMTCT** services or to support their current PMTCT programmes. These clinics are QE 2, Kakamega, Yopougon, Butare, Rwinkwavu, Uganda MRC, ANSS, World Wide Orphans, JCRC.

11 clinics want to gain access to **PCR** testing technology or expand the use of PCR in their clinics. (Phatsima, WWO, Kenyatta, Songea, JCRC, Kiwoko, CHUSS, Burere, Butare, Kirehe, ANSS.)

The **Mothers-to-Mothers-to-Be** (M2M2B) programme drew a lot of attention and 10 clinics want to implement it. M2M2B involves HIV-positive mothers who have recently given birth returning to maternity clinics to mentor, educate, counsel and support recently diagnosed HIV-positive pregnant women. (Yopougon, Kenyatta, Kibongoto, Songea, JCRC, Kiwoko, Uganda MRC, TASO, CHUSS, Coast.)

The **fast tracking of infant ARV treatment** was also identified as a crucial task and 13 clinics want to increase the number of children on treatment. (TASO, Kibuye, Chantal Biya, CHUSS, Kirehe, ANSS, Butare, Coast, FACES, Oshikulu, CAP, Kiwoko, Burere)

Nutrition

All attending clinics also indicated that they were willing to take up the challenge of another of the Forum's main themes – proper nutrition.

The establishment and expansion of growth monitoring (**anthropometry**) and nutritional assessments is aimed for in 13 clinics. (Nyangana, Phatsima, Oshikulu, WWO, Coast, Gertrude, Kakamega, JCRC, TASO, Kibuye, TRAC, Rwinkwavu, Butare).

The need to **employ a nutritionist or dietician** is also crucial and five clinics hope to achieve that goal this year – Coast, Kibongoto, Yopougon, CAP and Transmara.

Four clinics want to ensure that malnourished children receive **home visits** this year. This is to ensure that their living conditions can be adequately assessed and that follow-up care can be provided (Kibuye, TASO, JCRC, Nyangana).

As always, **income generation projects** receive high priority and eight clinics want to start such projects in order to empower mothers and caregivers (Phatsima, Gertrude, Kenyatta, JCRC, Uganda MRC, CAP, TRAC, Kirehe).

If you are from one of the 11 clinics which have not returned their grids, please pass it back to us. We are still waiting for the original task grids for Black Lion, ALERT, Tisugane, Job, Shimankana, Worcester, Hamburg, Dvokolwako, Newlands, Village Health Works, Lubumbashi, and Kibagabaga clinics. Please send them to us on melanie@teampata.org. as soon as possible.

3. The crisis of malnutrition and how teams plan to tackle it

Here is a truly shocking statistic: nine children die each minute from malnutrition. The World Health Organisation (WHO) has estimated that annually malnutrition causes the death of up to 5 million children under the age of five. In sub-Saharan Africa, UNICEF has calculated that nearly one third of children are underweight. And undernutrition has even further devastating effects as it is the underlying factor in half of all childhood deaths from infectious diseases.

These numbers are chilling, and we have to deal with the realities in our clinics and wards every day. All the teams at the PATA Forum last year agreed that drastic measures must be taken.

Teams felt that education was important, not only for the caregivers, but staff too needed to be educated and reminded about nutrition related issues. Teams also felt that the community at large needed to be taught about nutrition and intended to start media campaigns to do so.

Anthropometry was also found to be important. Teams wanted to acquire equipment and expand growth monitoring amongst their patients. Nutritionists needed to be hired. Home visits would be needed to better assess malnourished children. Teams also wanted to make ready-to-use therapeutic foods and other nutritional supplements available in their clinics. Some clinics also decided to start demonstration garden projects.

4. What is Plumpy'nut?

During the PATA Forum in Kigali, everyone wanted to know about Plumpy'nut – some of us even wanted to taste it! But those who were not there and have never heard about it, might very well ask: what is it?

Plumpy'nut is a type of Ready-to-Use Therapeutic Food (RUTF) that is used in the treatment of malnutrition. Developed by the French scientist, Andre Briend, in 1999, it is a paste made from peanuts and also contains vegetable oil, milk powder, vitamins and minerals. It is packaged in a foil wrapper and tastes sweeter than peanut butter.

Plumpy'nut has revolutionized the treatment of malnutrition, particularly in the setting of large scale famine relief, as it causes rapid and life-saving weight gain in young children. Not only is it more nutritious than the standard food assistance products, but the children can feed themselves the soft paste, and children do not need hospital admission for administration. In this way, community-based management of malnutrition frees up valuable hospital beds.

Plumpy'nut also has no preparation costs (such as cooking) and does not require refrigeration nor clean water to prepare. This also makes its distribution costs cheaper than conventional food aid.

Plumpy'nut has been recognised by the World Health Organization (WHO) as an important tool in famine relief. It has been successfully used by Medecins Sans Frontieres (Doctors Without Borders) in Niger since 2005, where recovery rates were 95% for moderately malnourished and 81% for severely malnourished children.

Project Peanut Butter, in Malawi, operates the first local factory for Plumpy'nut, and is successfully treating hundreds of children throughout the country. As the Project uses locally grown peanuts, the manufacturing cost for a course of lifesaving Plumpy'nut is only \$15.

They offer these three products at cost price:

Chiponde - ready-to-use therapeutic food for the treatment of severe childhood malnutrition

Chitukule - ready to use supplementary food to be used with wasted HIV+ adults

Soya Chiponde - ready-to-use peanut/ soy supplement for the treatment of moderate childhood malnutrition.

Project Peanut Butter is located along Makata Road in the Industrial district of Blantyre, Malawi. Products can usually be made within a few working days, if they are not in stock, so availability is immediate.

Inquiries regarding product usage can be directed to Heidi Sandige MD (heidisandige@hotmail.com) or Mark Manary MD (manary@kids.wustl.edu).

Orders can be made and pricing information obtained by calling Liyaka Nchilamwela (+265) 09 344 026.

5. Auntie Stella: A kit designed to discuss life skills with adolescents

Many children treated with anti-retroviral drugs have done very well and are now growing into adolescence. This success presents new problems as children grow up. Some PATA teams will remember that 'care of the adolescent' was a topic at the third PATA forum in Swaziland.

As a follow-up to the Swaziland meeting, an adolescent care planning workshop for the Western Cape Province of South Africa was organised and presented by PATA as a regional forum during May 2008.

A major outcome of this meeting was agreement by all participants on the need for staff training to deliver life skills education to HIV-positive adolescents in the Western Cape Province.

The Auntie Stella kit, produced by the Training Research and Support Centre (TARSC) in Zimbabwe (www.tarsc.org) is designed to provide adolescent friendly and highly pertinent life-skills education to young people – with and without HIV infection.

The Kidzpositive Family Fund (www.kidzpositive.org) has purchased 500 copies of the Auntie Stella kit, for use by HIV/AIDS counsellors throughout the Western Cape. TARSC trainers will provide ATICC, our local counsellor training unit, with initial instruction in the use of the kit. ATICC will then prepare the HIV/AIDS counsellors in our province.

This project will pilot Auntie Stella for possible use throughout the Paediatric AIDS for Africa (PATA) network. It is expected that French and Portuguese translations (already prepared) will be available for the project to be extended to all sub-Saharan countries.

For more information, go to www.tarsc.org and click on the 'Auntie Stella' link.

6. A Zimbabwean story – Zvandiri

The book *Our Story* was written by members of the Zvandiri Support Group from Harare, Zimbabwe. This HIV/AIDS support group consists of children and adolescents aged 8 to

18 years. As everyone in the support group is HIV positive, they chose the Shona name of “Zvandiri” for themselves, which means “as I am”. They cannot change who they are, but must live with HIV and accept it, as should others.

By sharing their experiences they aim to help other children and teenagers to understand more about the disease and what it means in their lives. More importantly, the book tries to tell other HIV positive children that they are not alone in their sadness and fear, and that there is still hope for their future.

The logo for the Zvandiri Support Group shows a rock with an open door and the sun rising behind it. The rock represents the children’s hearts, hardened by years of untold suffering. But the door opening it is the support group, which has helped them to share their experiences and learn together; and has given them hope for the future.

Our Story consists of quotes from the children and adolescents who were fearlessly honest and open in discussing their experiences. Here are some extracts from the chapters on how they felt before and after they were diagnosed with HIV:

“In the beginning, I wasn’t happy because no one was telling me what was happening, why I was sick. I couldn’t play with my friends.”

“When I was told I was positive I thought my life had ended. It took me quite some time to accept but I am glad I am still alive.”

“I was scared of my status. I was frightened and felt so alone, like I am going to die.”

The disease of HIV is explained, using the metaphor of “Warrior CD4 Cells” that protect the body. *Our Story* is illustrated with beautiful watercolour paintings which help to explain these ideas.

But the main message of this book is to give hope to other children living with the disease:

“...I know you will live a long time, because it’s the same as other illnesses, like high blood pressure, asthma or diabetes. So there is no need to fear.”

“Some give up and say they will die. They are wrong. You can get treatment and live longer.”

To get more information on this book and the Zvandiri Support Group, please contact Margie Hollands on dr.margiep@gmail.com

7. Colour-coding medicine bottles

It was clear from discussions among pharmacists at PATA Forum 2008 that caregivers sometimes got confused when it came to following directions on how to use medication, the doses given and even just having problems discerning between different medications.

This problem is made worse by the patients often attending with different caregivers at different pharmacy visits. These caregivers need to be re-educated as to how to use the medication again. Illiteracy amongst the caregivers can also hinder effective administering of the drugs.

A few of the pharmacists told the rest of their peers that they were able to largely resolve these problems by colour-coding the medicine bottles. That way it was easier to communicate the numbers of the different types of medication that needed to be given without the, often new and illiterate, caregiver having to remember difficult and foreign trade names. Many of the other pharmacists have now expressed interest in starting their own colour-coding of medicine bottles.

In the USA, a pharmacy company has designed a new shape of bottle for medicines that has more space for larger writing. It has done this by turning the bottle on its head, literally and flattening the usually rounded body of the bottle into a tapered rectangle. This allows for easier reading of the bottle because the bottle is no longer curved and also provides a greater surface area for medication directions.

Interestingly they have included a colour coded bottle top in the design so that different family members can distinguish between their medications and each others. You can see the new bottle here: <http://nymag.com/nymetro/health/features/11700/index1.html>

If you have found any other strategies that help to make medication consumption easier and more understandable for patients and caregivers, please contact PATA.

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